No decision about us without us.

Comments on the Illinois Section 1115 Draft Waiver

Next Steps appreciates the opportunity to comment on the draft waiver proposal, "Pathways to Transformation." While we know that this is common to say, it is particularly true of us. We are people with lived experience of homelessness, of active mental illness symptoms, of substance use and abuse. We are people who have used, are using, or may use in the future the services that are being transformed.

Too often we do not get the services we need or want but only the services that powerful forces want to give us. The system needs to be transformed and we are glad that Illinois is attempting to do so. We are proud and grateful that Illinois is asking our advice.

As requested by the Governor's Office consultants, we are providing comments to address the four "Pathways" identified in the waiver proposal. Before discussion of each Pathway, we offer several general comments:

- While the proposal addresses the development of supportive housing services for individuals, it does not follow a Housing First model. "Housing First approaches are based on the concept that an individual or household's first and primary need is to obtain stable housing, and that other issues that may affect the household can and should be addressed once housing is obtained." [i]

- We find the present system incredibly arcane and impossible to understand. We do not know what services are available to us or how to access them. We cannot understand various requirements for services. Often the only people who understand the requirements are the people who are offering us services. At least in part, they want us to use these services because they will be paid by Illinois. I suppose they also want us to use these services because "if all you have is a hammer, everything looks like a nail." Thus it is impossible for us to fully direct our care. We hope the new system will be much clearer and "consumer"-directed. (We do not like term "consumer" but we want you to understand.)

- Recovery is not only possible but should be expected. Recovery is "a process of change through which individuals improve their health and wellness, live a self-directed life, and strive to reach their full potential." (*Substance Abuse and Mental Health Services Administration [SAMHSA])* Through the Recovery Support Strategic Initiative, SAMHSA has also delineated four major dimensions that support a life in recovery:

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- ***Home:*** a stable and safe place to live;
- ***Health*****:** overcoming or managing one's disease(s) as well as living in a physically and emotionally healthy way;
- ***Purpose:*** meaningful daily activities, such as a job, school, volunteerism, family caretaking, or creative endeavors, and the independence, income and resources to participate in society; and
- ***Community:*** relationships and social networks that provide support, friendship, love, and hope.

- The waiver proposal is incomplete, missing information important to an understanding of the proposal, including – for example – an exact description of the services "SMHRF" will provide or the cost of those services. Without additional information, it is difficult to understand the impact of the waiver proposal or to take a position of support for the proposal as a whole.

- The proposal addresses behavioral health service and system issues significantly in positive and negative ways. More detail is identified below in "Pathway 4."

- The proposal, in our view, does not take full advantage of its potential to move our health care system away from an over-reliance on institutions and the "medical model" and toward community-based intervention, housing and support.

We will elaborate on these points in addressing each "Pathway" below.

Pathway 1: Transform the Health Care Delivery System

The waiver proposes new "provider-driven" models. This is simply wrongheaded. It is a case of the fox not only guarding but designing the hen house. Do not misunderstand: many of the people and organizations that provide us services are dedicated and the services they provide are invaluable. As one of our former leaders, Helen Morely, said, "I will die if you cut my services." The services were cut and she died. However, it is human nature, and the capitalist system depends on it, that people and organizations want to make more money.

While saving money is important, much more important is that,

"[i]n fact, persons with serious mental illness (SMI) are now dying 25 years earlier than the general population."[ii]

This is the problem, not that we are a "high-cost and highly prevalent clinical problem." [iii] By the same token, the purpose is not "long-term behavior change" but recovery.

If "health care reform will …. positively impact health outcomes and the quality of care" it should not matter that it will "negatively impact hospitals' bottom line." [iv]
Nor should the state pay for closure and conversion of institutions. They were paid, well paid, to provide a service; and when that service is no longer wanted, they should bear the burden. I do not compensate stores that provide DVD rental when I switch to Internet streaming. This is an example of powerful forces getting paid. Given the fiscal crisis in Illinois, this money can only come from other badly needed services. This is robbing Peter to pay Paul.

Pathway 2: Build Capacity of the Health Care System for Population Health Management

It is difficult to see the relationship of this pathway to Housing First. The focus is on the state health department, local health departments, local hospitals and community health centers, with incentives paid to health plans for creating "health interventions" and the creation of "regional hubs." "Health interventions" are not defined so it is difficult to understand what is proposed.

Pathway 3: 21st Century Health Care Workforce

We endorse the workforce objectives outlined on page 22 of the draft waiver proposal. Many areas of Illinois have been designated as "health professional shortage areas" by the federal government. Clearly, Illinois needs to focus on increasing the number of physicians, non-physician providers, health care professionals and community health care workers. It is unclear in the proposal, however, how broadly the term "community health care worker" will be applied and what classifications of employees may become involved in "21st century health care workforce" development activities. It should include increasing the number of trained peers and peer services. Now there are only approximately 150 CRSS. This is not due to a lack of interest or ability but because of the cost and the lack of work available.

We support the proposal that "certain health workforce training programs and related supports be treated as Designated State Health Programs (DSHP). The proposal does not, however, identify which training programs will be identified, nor does the proposal identify a dollar amount for this effort.

We support the proposed loan repayment proposals and encourage the state to include a range of licensed and/or certified professional classifications (i.e., social workers, psychologists, clinical professional counselors, peer specialists) as part of the proposed program. Illinois should establish and include in the proposed loan repayment proposal a certification process for

"residential service associates," qualified staff who serve in a capacity for homeless services' supportive housing similar to the "residential service associate" role in mental health services.

Pathway 4 LTSS Infrastructure, Choice, and Coordination

We enthusiastically support the waiver proposals to:

- Rebuild and expand its home- and community-based infrastructure, especially for those with complex health and behavioral health needs.[v]
- Expand Assertive Community Treatment (ACT) teams and Community Support Teams
- (Include SOAR (SSI Outreach, Access and Recovery) application work as a reimbursable activity under the proposed incentive pool for behavioral health providers. It should also specifically be included as a reimbursable activity for homeless services. The SOAR process is equally or perhaps more important for individuals experiencing or at risk for homelessness. It provides the best hope for many of us to gain some limited ability to afford basic needs, including food and utilities.
- Expand supportive housing for individuals with mental illnesses. As the waiver states, supportive housing is a necessary component of any effort to care for us. Permanent supportive housing has long been identified as an evidence-based practice for individuals with serious mental illnesses, as formally recognized by the federal Substance Abuse and Mental Health Services Administration While we strongly endorse the proposed expansion of supportive housing services for people like us, we are concerned that the state has chosen not to include supportive housing in the State Plan for Medicaid services, and plans only to include the minimal contract language that managed care organizations (MCO) and managed care community networks (MCCN) "consider" the use of supportive housing and will not include this "consideration" in contract language for care coordination (CCE) and accountable care (ACE) entities. Further concern is raised by the statement that this "considered" supportive housing would be financed through an add-on to the managed care administrative reimbursement. Simply stated, although managed care organizations should "consider" the use of supportive housing, the actual commitment of resources is not there. This is not a wise position for the state, and will cost more and bring less population health improvement.

We reserve opinion about the waiver proposal's stated plan for the state to develop common service definitions, provider qualifications and reimbursement schedules, simplification of the claims payment processes for both fee-for-service and for managed care encounter data, the universal assessment tool and the undefined "tiered" service approach. The "devil is in the details" for these planned changes. The potential for "unintended consequences" by collapsing nine existing waivers, mental health and substance abuse services into one mega-waiver is large and, potentially, de-stabilizing for unprepared and resource-poor community providers. Attention must be paid to supporting these organizations, preserving and enhancing their service

capabilities, establishing reimbursement strategies that rebuild a weakened system and supporting administrative and information technology capabilities.

We are opposed to the waiver proposal's request that Specialized Mental Health Rehabilitation Facilities (SMHRF) services be treated as costs not otherwise matchable (CNOM) for the five-year waiver period. We think this will prevent the request's approval by the federal government because the SMHRF is formally designated as an Institution for Mental Disease (IMD) and does not qualify for FFP. IMD services are excluded under the well-known IMD exclusion contained in the Social Security Act.

More than any other state, Illinois has relied on nursing homes, including those classified as IMDs (now relabeled as SMHRFs), to warehouse people with mental illnesses. Illinois' recent decision to move away from this reliance by entering into the *Williams v. Quinn* and *Colbert v. Quinn* consent decrees committed the state to a system of more humane, efficient and non-institutional care as required by the Americans with Disabilities Act and the United States Supreme Court's decision in *Olmstead v. L.C.* There is no reason to abandon or delay the implementation of these consent decrees by using federal funding for these institutions. Waivers should not be used to increase our institutions. **An institution is not a home.**

Once again, we thank the Governor's Office for the opportunity to present written comment about the draft waiver proposal. This is too long but, as Mark Twain said, "We would have written something shorter if we had more time." Our staff and Board of Directors are at your disposal for additional input or any questions you may have.

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[i] • From Wikipedia, the free encyclopedia

[ii] Morbidity and Mortality in People with Serious Mental Illness, National Association of State Mental Health Program Directors (NASMHPD) Medical Directors Council, 2006

[iii] Page 14

[iv] Page 17

[vv] (Page 38)